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SUPPORT SERVICES TO FAMILY CAREGIVERS OF OLDER ALBERTANS

**Background Paper prepared for the
1988 Annual Report of the
Provincial Senior Citizens Advisory Council**

Alberta
SENIOR CITIZENS SECRETARIAT
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I am pleased to present this background paper prepared under the direction of the Provincial Senior Citizens Advisory Council for the 1988 report to the Minister of Social Services.

We hope that it will be helpful to all who are concerned and interested in older people.

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A. *Introduction*

Support service to Albertans who care for their older family members is a relatively new initiative and has seen only minimal development. Although professional literature abounds with evidence that the family is an important source of support and care for its elderly members,[1] service development has focused primarily on institutional care. It has been suggested, for instance, that unless public policy changes, the institutional care sector has a drive towards self-preservation and growth that overshadows the development of any alternative service option.[2]

Any services to family caregivers of seniors appear to be secondary to services to older people. As ancillary services, they are delivered almost as an afterthought.

This paper reviews programs in Alberta which, in one way or another, provide services or benefits which support family caregivers of people 65 years and over. It also looks at programs for people who care for adults who are not senior citizens and for people who care for disabled children. There is as well discussion of programs in other provinces and countries that have features which may be helpful to people who care for older people in Alberta.

B. *Support Services Needed by Caregivers*

Support services to family caregivers are seen as falling into six broad categories:

1. outreach,
2. information, education and training,
3. emotional support and counselling,
4. caregiving support and relief,
5. housing support, and
6. financial support.

1. Outreach to Caregivers

In the delivery of human services, it has been found that the very people who need help are often poorly informed about the services available to them. In fact, it has been recognized that to ensure services are used by those who need them, publicity and outreach are essential.[3] Family caregivers are no exception. They often fall into the role of caregiving unprepared and lacking knowledge about their new role and about the resources that are available to them. In addition, caregiving can have an isolating effect. The caregiver is frequently confined to the home, caring for the unwell person, and contacts with the outside community are lost. Unless a perceptive person reaches out to the caregiver at an early stage – for example, in the hospital when arrangements for caregiving are first made – a pattern of isolation and lack of support may begin. People living a shut-in life are difficult to identify and, therefore, hard to reach.

Of the programs that may bring support to family caregivers in Alberta, few of them offer active outreach to families providing care to the elderly. Exceptions to this are support societies and groups such as the Alzheimer's Society. Generally, caregivers come to the social agencies for help rather than the agencies reaching out to them. Organizations which help older people in need of support and care may solicit help from relatives on the seniors' behalf, but rarely see their role as being advocates for the caregivers. Only a few organizations are known, for instance, to have brochures aimed specifically at caregivers, with information about services and benefits available to them as care providers.

Caregiving relationships often begin when seniors are discharged from hospital. It is a time when care providers are easily identified at an early stage in their caregiving role. It is an opportune time to reach out with information about support services and the knowledge and skills required for caregiving.[4] And yet, the priority in a busy hospital is to ensure the patient has a place to go upon being discharged, rather than on providing outreach to the caregiver. At that specific time, it appears to be nobody's mandate to help the family caregiver of the older person to understand the needs of the patient and how to meet them. However, once the family is at home, "case finding" and outreach become far more difficult. In contrast, when one looks at services for the handicapped in Alberta, support to relatives in their helping relationship appears to be an integral part of service delivery.

If caregiving by family members is valued, then outreach from the very beginning – by hospital staff, physicians, home care staff – is needed, and should be continued. There should be ongoing monitoring of needs and provision of appropriate resource information.

2. Information, Education and Training

Historically, outreach came into being in social and health services as a means of providing information, rather than as a means of sharing empathy. Information is essential to help people make informed decisions. Studies have consistently shown that those who need the most help are often least informed about services and benefits available to them. People providing care for family members would appear to be no exception. As noted earlier, they come to caregiving by circumstance and not by choice. They tend to be unprepared for the task, and they usually learn the hard way – by trial and error.

In Alberta, information and educational services for people who care for others in their homes are not provided in any consistent way. There are, for instance, no handbooks for care providers about the range of support services available. Nor does anyone come automatically to the home to check with the family about how they are managing and what routines may be established to assist in the provision of care. Relief care, though available, is not widely advertised and is likely unknown to many caregivers. However, if the patient is receiving home care services from the Coordinated Home Care Program of the health units, education and information are often provided by Home Care staff.

3. Counselling and Emotional Support

Several municipalities in Alberta have projects funded by Family and Community Support Services (FCSS) and other services which provide counselling to families and individuals, including older adults and their families. Indeed, recognizing the need, some agencies provide specialized counselling services aimed specifically at seniors and their families, including group programs (e.g. "As Parents Grow Older" and other support groups).

Counselling family members and the people they are caring for is an important support service. The caregiving relationship can be a very stressful one.[5] Caregiving can be an emotionally and physically draining job. The responsibility for care often falls on one person. Shared caregiving in a family is quite infrequent,[6] but there is usually a good deal of criticism and resentment about how care is provided, nonetheless. Unresolved, long forgotten problems in family relationships may reappear and cause hurtful, destructive conflicts. In addition, the community may not be supportive. Health

care professionals may also be critical of the caregiver's efforts.

The caregiver often has dependent children and a spouse – all making heavy and conflicting demands on her.[7] Privacy may be severely strained. Spousal caregivers sometimes find it difficult to be isolated with a person who is dramatically changed. They may be faced with intimacies which they find they can no longer tolerate. It should be remembered that many of the caregivers of elderly persons are their spouses.

The list of dilemmas and pressures can go on and on, for the person who receives care as well as the person providing it. The result can be that the two of them feel they are locked in a house together, with no one to understand what they are feeling and experiencing, and no one to provide them with support and concern.

Some people may question the need for social workers to be a part of the Coordinated Home Care Program. At the very least, however, home care programs need to train staff to recognize that the people they serve are often in a state of emotional upheaval. In such cases, clients need to be referred to counselling. Waiting until the caregiver asks for help may be too late.

4. Caregiving Support and Respite

Home nursing, personal care, rehabilitation services and homemakers and home help are offered through the Coordinated Home Care Program. Homemakers and home help are provided as well through several FCSS agencies in the province. However, these services are usually thought of in terms of the needs of the senior requiring care. Help to the caregiver may only be considered if the caregiver is also elderly and frail and in need of care. This may be a technical point to meet program administration needs. It does, however, reflect public attitudes toward caregivers. Public policies do not yet ensure that services reach out to caregivers, to support them in their role and in their own need for well-being.

The following caregiving support and relief services may be helpful to family caregivers in Alberta:

a) *Home Care*
Under the Coordinated Home Care Program regulations, *personal care and homemaking services* "shall be provided." "Personal care services" means "hygiene care and assistance with personal activities with daily living." "Homemaking services" include:

i. adult care and child care,
ii. routine housecleaning, laundry, ironing and mending.

The program may provide heavy housework service and handyman service.[8]

Although the regulations specify what "may" and "shall" be provided, each health unit jurisdiction has its own budget for Home Care and determines, within the terms of the regulations, which services will be provided and to what degree. Because of financial constraints, many Coordinated Home Care Programs have decided to limit their hours of service. The trend is toward provision of care to those needing less service.

b) *Family and Community Support Services (FCSS)-funded Agencies*
FCSS-funded agencies, in some areas, provide a variety of services to reach out to

and help seniors. FCSS-funded programs are open to community requests and in some instances have already developed *caregivers' support services.*

c) *Respite Care*
Some auxiliary hospitals and nursing homes in Alberta have operated a *holiday respite* service for several years. They provide care for the care receiver so the care provider is able to have a holiday, etc., and *convalescent care* if the caregiver becomes ill. Lodges are beginning to offer a similar service. However, in some instances the service appears to be available more as a means of filling empty beds, than as a committed, specialized service.

Part-time placement – for two to five days each week – may also be available on a regular basis. Again, though hospital districts may be committed to assisting family care providers, the institutions providing care need to be concerned about revenue. They are, therefore, reluctant to get locked into part-time care unless the "part-time bed" is filled and producing revenue every day of the week.

Respite care service is not widely advertised, and it is possible that many caregivers are not aware of it. It can be difficult to make use of the service at times, given the flexibility needed to meet the individual needs of each family.

Respite care in the home is particularly difficult to obtain. Very few agencies provide it. There are no clear-cut funding subsidies for such care. Coordinated Home Care administrations, though permitted to provide "adult sitting" under homemaking services, tend to provide minimal relief care to caregivers – usually during the hours the homemaker is doing housecleaning.

To be an effective community support service, respite care services need to be well advertised, attractive, available both in the home and in a group setting, flexible to meet the needs of the family, and able to reach out. They also need to be affordable and, if the care is given in a centre rather than in the home, they need to be associated with a reliable transportation service.

d) *Day Hospitals*
Day hospitals are available only in a few centres in Alberta. They are not intended to be respite care providers, but rather to provide active rehabilitation. They can play an important role in helping caregivers better understand the behaviour and needs of the patient, and assist in developing routines, shortcuts and better ways of doing things, and suggesting aids to daily living, etc. Day hospitals may also help the care receiver to get acclimatized to visits into the community, and thereby accept going into a day support program following discharge from the day hospital program.

e) *Day Support Programs*
Day support programs are again only available in a few centres in Alberta. They provide relief for the caregiver, giving her/him a rest from care provision. As opposed to respite care in the home, day programs allow the care provider time and privacy at home, by taking the cared-for person out for the day. This can offer the care receiver an important link with the community, preventing the insularity and fear of going out that can be problems for shut-ins.

Day support programs in Alberta are dependent on uncertain financing arrangements, donated space, and the determined efforts of community boards and staff to keep them operating.

f) *Emergency Response Systems*
These systems, such as the ones administered from Bethany Care Centre in Calgary, and the Royal Alexandra Hospital and Good Samaritan Auxiliary Hospital in Edmonton, are seen as a caregiving/support service to help people at risk to live in the community on their own. This service could also be helpful for seniors who receive care from their family but who are left on their own during the day while the caregiver works.

Relief care service organizers are sometimes surprised, when they start a service, that they are not overwhelmed with demands for care. The reasons for the slow demand may include the following: consumers and professionals often do not know of the service; the person who receives care may not want to use the service because of fear of a new, unknown environment; therefore, the care provider is faced with a relative who resists the service, and feels guilty about pushing the issue; in addition, the caregiver, having been locked into a situation for some time, has also developed an accommodation that makes her/him find respite care difficult to accept initially.[9] "It's too much bother, it isn't worth the effort" or "nobody knows how to look after him properly." It is important for the intake worker of a respite care service to be aware of the fears that may have developed, and to be warm, accepting, reassuring and accommodating, and to encourage care providers to take advantage of respite programs if that is what they want.

5. Housing

Housing support measures may assist families in maintaining a closer helping relationship as their parents become frail or ill. Although some older people prefer to live independently from their children, even if it means going into a nursing home, others and their families feel that a close living arrangement will allow them to be supportive of each other without necessarily losing independence or privacy.

There are several housing support programs for seniors in Alberta that may be of help to the caregiving family and the senior.

a) *Community Housing*
The older person and the caregiver may qualify, if one of them is over 65, for senior citizen rental housing. Rent is charged at 25 per cent of income.

b) *Rent Supplement Program*
The older person and the caregiver, by renting in housing developments approved under this program, qualify for reduced rental rates based on their income. "Priority is given to those most in need."

c) *Senior Citizens' Renters Assistance*
Any senior renting accommodation may receive a renters rebate of $1,200 annually, unless living in subsidized rental housing whereby he/she may receive $600 annually.

d) *Rural and Native Housing Program, Rural Emergency Home Program and Rural Home Assistance Program*
These are three programs, available in some rural areas, which may be helpful to seniors and their caregivers.

e) *Property Tax Reduction*
Senior citizens are eligible for a tax reduction on their property.

f) *Seniors' Home Improvement Program*
This is only available to the senior citizen (or widow[er] of one) if he/she is a homeowner. Money is made available, based on income, for improvements and repairs to the home.

g) *Home Adaptation Program*
This grant is provided to homeowners and tenants who are wheelchair users (and who have resided in Alberta for at least one year) on an income-tested basis. The purpose is to adapt the residence for the wheelchair user. For the older person living with the caregiver/homeowner, the caregiver may apply as the landlord or the older person may apply as the tenant. (The grant is only available if the older person has "independent accommodation" with bathroom and kitchen.)

h) *National Garden Suite Demonstration Project*
This housing option for the frail elderly requiring family support is not, as yet, available to the public. Only one unit has been completed in Alberta, and is being shown at various locations across the province. It is similar to the Australian "Granny Flats" development, under which a prefabricated, self-contained unit is installed for the older person in the garden of his/her family's home. It shows promise as a living arrangement which encourages close family ties and opportunity for independence and privacy between older parents and adult children.

i) *Housing Support in Some Other Provinces*
Alberta does not appear to be unique in investigating housing support given to encourage caregiving by a family to its elderly members. At least two other provinces are known to be experimenting with similar demonstration programs. In Ontario, it is the *Granny Flat Demonstration Project*. Saskatchewan's *Elder Suites* program differs somewhat by making provision for *attached* as well as *detached* elder suites.

Ontario has other housing support programs that may be helpful to caregiving, but these programs seem to have been instituted more out of concern for a tight housing market than in response to the needs of the elderly.

6. Financial Support

In general, there appears to be no organized financial support system available to care providers in Alberta -- beyond some of those noted under (5) *Housing* (low-interest loans, grants and rent subsidies for housing). The Home Care Program may fund or deliver services, but does not provide funds to caregivers to purchase services on their own. Social Allowance may be available to families if the caregiver is a spouse and if the physician advises the care is essential. Social Allowance, however, is not available to enable an adult child to provide care to a disabled parent. Upon medical recommendation, parents who receive Social Allowance or Assured Income for the Severely Handicapped (AISH) and who require help or care at home may have the cost of service covered by these programs, but *only* if provided by non-family members!

In contrast, Norway and Sweden provide monthly financial support for the care provider if the caregiving limits the helper's ability to get other employment or requires her/him to leave the work force. For a person who has

cared for an elderly or disabled relative, a pension is available if the services have led to a permanent reduction in the possibility of obtaining employment. In addition, the local home help office may contract for services with the caregiver, and provide not only training, if necessary, and supervision, but also payment for service.[10]

Most other industrialized nations (excluding the United States, Canada and West Germany) have some form of "attendance allowance" (a cash benefit paid on behalf of permanently disabled persons who require either full or part-time care by another person at home). The payments are usually covered through the old age or disability insurance programs. There are, however, wide variations among these nations in benefit levels and qualifying conditions.[11]

Saskatchewan has a form of attendance allowance which provides compensation for a caregiver to assist a member of the family, if nobody else is available, and who then is employed and trained by the Home Care Program. There is the additional requirement that the caregiver may be asked to serve others in the area.[12]

Two other interesting financial support programs are the Veterans Affairs Canada project, called the Aging Veterans Program, and the State of Wisconsin Community Options Program. Both approach the need for care by providing funds to the disabled person to purchase service rather than – as in the Saskatchewan and Scandinavian programs – for the caregiver to be paid directly by the funding agent. Douglas W. Nelson in *Community Options Program in Wisconsin,* notes that in that state, "we said that we ought to *empower* the client by providing reimbursement for any implemented case plan up to the amount we would have spent had that individual become a . . . nursing home resident."[13] The Veterans Affairs Canada program of financial support to purchase care is more stringent. It allows the veteran to hire a care provider who may be a friend or relative as long as she/he does not usually live in the veteran's home.[14]

There appear to be two opinions about giving people money to purchase their own caregiving services. The one which suggests that people should be given the money to look after themselves and that they are the best judges of what they need is expressed bluntly by Nelson. He talks about "client empowerment" and "we think individual client preferences usually reflect a pretty good judgement about what the individual objectively needs." And "In the end if I had to choose between the cost efficiency instincts of an 87 year old widow and those of, say, a Medicare certified home health agency, I'd go with the widow every time."[15]

The opposing view suggests that purchasing caregiving services on behalf of the client is a more sensible option in providing service, particularly to people who are frail and handicapped. It is suggested that finding reliable service providers is a difficult task and that standards of service are maintained if agencies provide or purchase services. In addition, our system is too complex for individual service recipients to tackle.

C. Services for the Handicapped

Services for the Handicapped (Alberta Social Services' Community Rehabilitation Program and Community Resource Management) were reviewed to examine what initiatives in that program may prove helpful in planning support services to family caregivers of senior citizens.

As in the case of the Coordinated Home Care Program and Alberta Mental Health Services, there is considerable variation from region to region in the Services for the Handicapped Program. The differences may not only be in the services available regionally, but there may also be different "philosophical interpretations" of the program. The way services are developed and delivered depends "on the readiness of the regional staff and the community." Further, it is suggested that it may be an injustice to have a universal program because needs and resources may differ from region to region.

The regional representative of the Community Resource Management Branch, who was interviewed for this review, suggested that it is imperative that the program focus on the individual and not the program. With that in mind, the consultants in Community Resource Management believe in the development of options for clients, to give them a choice. Particular attention is paid to client support and empowerment. An example is a project pioneered by the Calgary Association for Independent Living: the Joshua Committees, with their personal support networks. The handicapped person works with a group of committed people who will provide an effective support system to break down the barriers which hold the handicapped person back in living life as he/she chooses. This concept, when considered in relation to family caregivers and persons receiving care, may be translated into a community and/or family network which supports the senior and the caregiver in accomplishing not only support and respite, but some measure of self-fulfillment.

Because of the attractive features of the Joshua Committee principles, the region has attempted to complement them through what it calls *Individual Service Planning/Funding*. The process is initiated with an interested group of people – e.g. family members – and with the individual included in all aspects of planning. The group first determines what supports the person needs throughout the day, and then who does what to support that person. Breaking down the barriers which hold back the disabled from making their own choices is emphasized. Leadership for developing the service plan, according to the Community Resource Management representative, sometimes comes from that office, but often comes from the family, another community agency or an advocacy group.

Relief to care providers is formalized only for families caring for handicapped children. Relief care is paid for by the department, with the family paying $2 per hour - up to $10 per session. There is a limit to the number of hours a family may get. In addition, through Child Welfare, there is a yearly allocation made for relief services to families with handicapped children. It provides for babysitting, transportation, specialized equipment and medication. An agreement is worked out according to need (not financial need), and the family receives the money to purchase service.

With handicapped adults being eligible (on an income-tested basis) for the Assured Income for the Severely Handicapped (AISH), any service needs, when properly authorized – including relief care – would be covered by AISH Plus if the person was already receiving AISH.

D. Alberta's Present Direction

Alberta is fortunate to have a network of health and social services with the potential to meet the needs of older Albertans. Of concern in

recent years is not so much that services are unavailable, but rather that the choice of services provided has a bias toward institutional care.

Institutional care is visible and well-known while caregiving in the home by family and friends suffers from a lack of visibility. Caregivers are usually alone, isolated, weary from the demands of caring, feeling helpless and unsupported.

The Committee on Long Term Care for Senior Citizens in its report *A New Vision for Long Term Care – Meeting the Need* says:

> *Our goal is to make recommendations which foster and promote a continuum of appropriate long term care for the aging population, emphasizing independence and quality of life in a community and family-based environment, commensurate with the resources of the province and the individual.*[16]

The Committee addresses this goal with strategies to promote wellness, to increase volunteerism, to expand community services, to support independence, to develop special housing, to improve gerontological training, etc. Not much acknowledgement, however, is given to the important role of the family as a caregiving unit. Strategies to support the family are not addressed beyond suggesting increased respite care.

Government policy and service provision appears to be slow in recognizing the contribution of the family and in supporting families who provide care. The slow acceptance of day support programs and flexible, easily accessible respite services are examples. A similar measure that has little acceptance is the unavailability of social allowance support for family caregivers other than spouses.

E. The Importance of Family Caregiving

> *"The amount of care provided by families to ill elderly relatives in most developed countries far outweighs that provided by the public or voluntary sectors....Not only is family care the predominant pattern, it also seems to be the pattern desired by the elderly. In times of crisis caused by ill health or death of a spouse, it is to family members that the elderly most frequently turn for assistance. In fact, studies from a number of nations indicate that older persons in need of help turn first to spouse, then to children, then to other relatives, and only last to formal agencies for assistance."*[17]

In the United States, for instance, "the 5 percent of persons over 65 and over who are in institutions at any one time...are outnumbered two to one by equally disabled older persons who live in the community, primarily in the homes of their families."[18]

It is not known at this time how many older adults in Alberta receive care at home. Certainly, access to institutional care is easier in Alberta than in the United States, where the cost of care to the patient is usually prohibitive. However, it is generally suggested that the number of older adults cared for at home is significantly higher than the number who are institutionalized.[19]

The Committee on Long Term Care for Senior Citizens was "asked to develop a plan for meet-

ing ... (the) challenge in partnership with service providers, community groups and the people of Alberta."[20] The challenge, then, is not only to develop the plan in partnership with those people who provide institutional care, but also to develop it in consultation with the other significant caregiver groups, including the people who are currently caring for their spouses and parents.

F. Recommendations

RECOMMENDATION 1

To the Minister of Health

We recommend that government policy acknowledge the essential role the family has in providing care to frail and disabled older persons; we therefore recommend that the government ensure that care by the family be given priority unless otherwise indicated by the wishes of the person receiving care, the unwillingness or inability of the family, or the public cost if it is more than the cost of appropriate institutional care.

RECOMMENDATION 2

To the Minister of Health

We recommend that health care agencies working with older people recognize and increase their capability to support families involved in caregiving. This could include hospital discharge planning, in consultation with the patient and his/her family; making available information about community support groups; and having home care workers support, inform, educate and counsel family caregivers.

RECOMMENDATION 3

To the Minister of Health

We recommend that programs to relieve caregivers such as respite care in home and institutions, day programs, day hospital care and night care assistance be further developed.

RECOMMENDATION 4

To the Provincial Treasurer and to the Minister of Social Services

We recommend that financial support programs be considered for caregivers who are unable to work because of caregiving responsibilities and whose income and assets would make them eligible for such financial aid. This could be done either through tax concessions by both the provincial and federal governments or by income security programs, such as providing social allowance to other than spouses who are presently eligible.

RECOMMENDATION 5

To the Minister of Advanced Education and to the Minister of Health

We recommend that universities and other post-secondary educational institutions, as well as home care, be encouraged to include in any educational programs on aging, aspects of family caregiving for older adults.

RECOMMENDATION 6

To the Minister of Municipal Affairs

We recommend consultation with municipalities to assist them in reviewing and changing zoning regulations that prevent families from maintaining a closer helping relationship with older relatives or friends, since zoning regulations often prevent the use of garden suites and in-house suites. These zoning regulations could be lifted on an individual and temporary basis, in particular for garden suites.

FOOTNOTES

[1] Mary Jo Gibson, "Family Support Patterns, Policies and Programs," a paper presented at the Joint Meeting of the Gerontological Society of America and the Canadian Association of Gerontology, Toronto, Nov. 11, 1981. Reprinted in Mary Jo Gibson, and Charlotte Nusberg, *Innovative Aging Program Abroad,* (Westport, Conn.: Greenwood Press), 1984, pp 159-194.

[2] Mary Engelmann, "Towards an Effective System of Services for Semi-Dependent and Dependent Older Persons," *a background paper included in the Alberta Provincial Senior Citizens Advisory Council 1979 Report.*

[3] *Outreach to Alberta's Aging Population,* a paper prepared for the Provincial Senior Citizens Advisory Council, 1988.

[4] Jordan I. Kosberg in "Preventing Elder Abuse: Identification of High Risk Factors Prior to Placement Decisions," *The Gerontologist* 1985, XXVIII, Nov. 1, Feb. 1988, pp. 43-50, suggests, as a method for elder abuse prevention, a systematic assessment of the older person and the potential caregiver before the patient is discharged to the community.

[5] G. Eggert, C. Granger, R. Morris and S. Pendeleton, "Caring for the Patient With Long-Term Disability," *Geriatrics,* 1977, pp. 102-114.

[6] Mary Jo Gibson, *op. cit.,* p. 165.

[7] E. Brody, "Women in the Middle," *The Gerontologist,* 1981, XXI, pp. 471-480. In this article and others (Cantor 1983, Johnson 1983, Lee 1983, Stollen 1982, Troll 1971) it is stated that caregiving to elders is usually done by women.

Amy Horowitz, "Sons and Daughters as Caregivers to Older Parents: Differences in Role Performance and Consequences," *The Gerontologist,* XXV, (6), pp. 612-617. With people having smaller families and with the trend for an increased proportion of women in the labour force, the future availability of daughters to serve as primary caregivers to their old parents may be limited. However, with the decreasing emphasis on role distinction between men and women, sons may become more actively involved in the nurturing aspects of caregiving.

[8] *Coordinated Home Care Program Regulations,* Alberta Order-in-Council, approved and ordered July 31, 1985.

[9] William Rakowski & Noreen M. Clark, "Future Outlook, Caregiving, and Care-Receiving in the Family Context," *The Gerontologist,* 1985, XXL, p. 618. The authors note research that indicated that family members persisted in unassisted caregiving even to the detriment of their own health, despite having knowledge of outside services that were available to them.

[10] Sister Jean Golden, *Assistance with the Provision of Care*, a background paper included in the Alberta Provincial Senior Citizens Advisory Council 1985 Report.

[11] Mary Jo Gibson, *op. cit.*, p. 169.

[12] Sister Jean Golden, *op. cit.*

[13] Douglas W. Nelson, *Community Options Program in Wisconsin*, a talk delivered at the 35th Annual Conference of the National Council on Aging, San Francisco, 1985; available from the Senior Citizens Secretariat.

[14] Sister Jean Golden, *op. cit.*

[15] Douglas W. Nelson, *op. cit.*

[16] "A New Vision for Long Term Care – Meeting the Need," Government of Alberta discussion paper, *Report of the Committee on Long-Term Care for Senior Citizens*, February 1988.

[17] Mary Jo Gibson, *op. cit.*, p. 164.

[18] *Ibid.*, p. 164.

[19] For instance, Mary McCabe, Director of the Edmonton Home Care Program, suggests that there are far more people receiving long-term care at home than in long-term care institutions.

[20] "A New Vision for Long Term Care – Meeting the Need," *op. cit.*